

Office of MaineCare Services

HIV/AIDS Waiver – 2020 Provider Survey Analysis

Background:

The Department of Health and Human Services, Office of MaineCare Services (OMS) operates an HIV/AIDS program under a waiver approved by the U.S. Centers for Medicare & Medicaid Services (CMS). This waiver allows the Department to provide limited MaineCare (Maine Medicaid) coverage to HIV-positive Maine residents who have an individual gross income less than or equal to 250% of the Federal Poverty Level (FPL), as well as providing care management to all HIV-positive MaineCare members, those with an individual income at or below 138% of the FPL. The HIV/AIDS waiver program began in July 2002 and CMS has approved it for renewal through December 31, 2028.

Survey Objective:

The goal of the Provider Survey is to gather feedback and find areas for improvement so that the program effectively supports providers and thereby improves care for members. In the past year, an influx of immigrants and the COVID-19 pandemic significantly increased the demands on providers. Impacts included an increase in patients' behavioral health concerns, provider adoption and/or expansion of telehealth options, workforce shortages, and delay of routine preventive care. In addition, COVID disproportionately affected the clinical outcomes of the Black, Indigenous, and People of Color (BIPOC) communities. Each year, OMS adds new questions to the survey to address emerging clinical and social issues. In this year's survey, as part of OMS' efforts to increase the focus on health equity in all our programs, we added questions about barriers to care and how we might address them. OMS is particularly interested in providers' awareness and use of Community Health Workers (CHW) to assist their patients in obtaining the full spectrum of care they need. We share this survey analysis with CMS as part of the annual report for the MaineCare waiver, as well as with the HIV Advisory Committee (HIVAC) and the Maine CDC's Integrated HIV Prevention and Planning committee.¹

¹ The HIV Advisory Committee was established to advise the Office of the Governor and state, federal and private sector agencies, officials and committees on HIV-related and AIDS-related policy, planning, budget, or rules. The HIV Advisory Committee also assesses emerging HIV-related issues and trends, initiates and responds to legislation, and prepares and presents an annual report on the status of HIV in Maine.

Survey Process:

OMS conducted the 16th annual provider survey at the beginning of 2021. Surveys were mailed to infectious disease specialists and primary care providers who, at the time of the mailing, were treating MaineCare and waiver members with HIV/AIDS. This year, OMS also offered the survey online, through SurveyMonkey. Three hundred nine surveys were mailed, and 76 providers responded (5 of those providers responded online). This data shows a response rate of approximately 25%, compared to 34% last year. This reduced response rate was likely due to the impact of COVID-19. The lower response rate may mean that the feedback is less representative of the whole group of providers.

The survey questions covered the following areas:

- Medical practice specialty
- Number of HIV/AIDS patients managed or co-managed, and number of patients who are new Mainers (newly established in the US, such as immigrants and refugees)
- Provider awareness of current treatment guidelines and new recommendations for HIV/AIDS patients
- Provider awareness of funding and training opportunities through the Maine AIDS Education and Training Center (MEAETC)
- Provider awareness of the MaineCare HIV/AIDS waiver
- Provider awareness of the Ryan White/AIDS Drug Assistance Program (ADAP)
- Barriers affecting adherence/compliance with medication
- Provider awareness and usage of CHWs
- Providers' feedback on how the HIV/AIDS waiver could best support them
- Providers' preferences on receiving letters and updates via an HIV-specific listserv

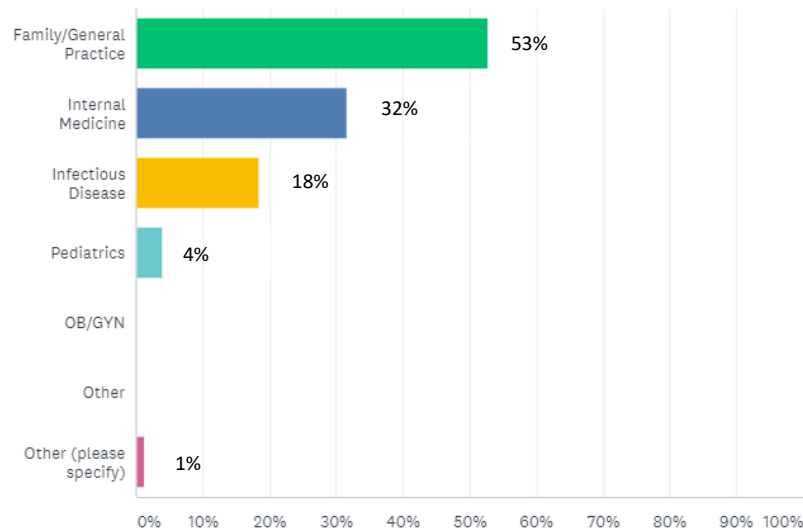
Note: Not all participants answered all questions, and some participants selected multiple answers on a question; therefore, the number of responses vary from question to question. The percentages in the charts are rounded to the nearest whole number based on the number of responses.

Results:

Figure 1: Practice Specialties

Identify your practice specialty

Answered: 76 Skipped: 0



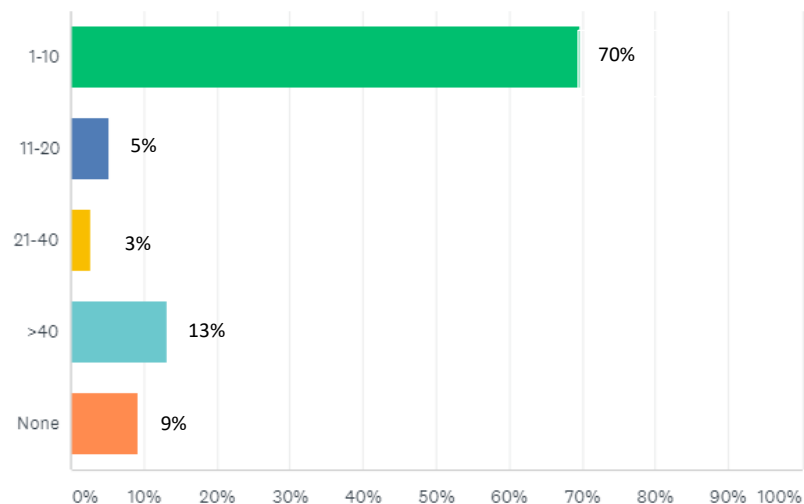
ANSWER CHOICES	RESPONSES	
▼ Family/General Practice	52.63%	40
▼ Internal Medicine	31.58%	24
▼ Infectious Disease	18.42%	14
▼ Pediatrics	3.95%	3
▼ OB/GYN	0.00%	0
▼ Other	0.00%	0
▼ Other (please specify)	Responses 1.32%	1
Total Respondents: 76		

Figure 1 shows that of the providers who responded, the majority (53%) were family/general practice, compared to 57% last year.

Figure 2: Number of Current HIV/AIDS Patients

How many patients living with HIV/AIDS have you medically managed or co-managed (for any diagnosis) in the last 12 months?

Answered: 76 Skipped: 0



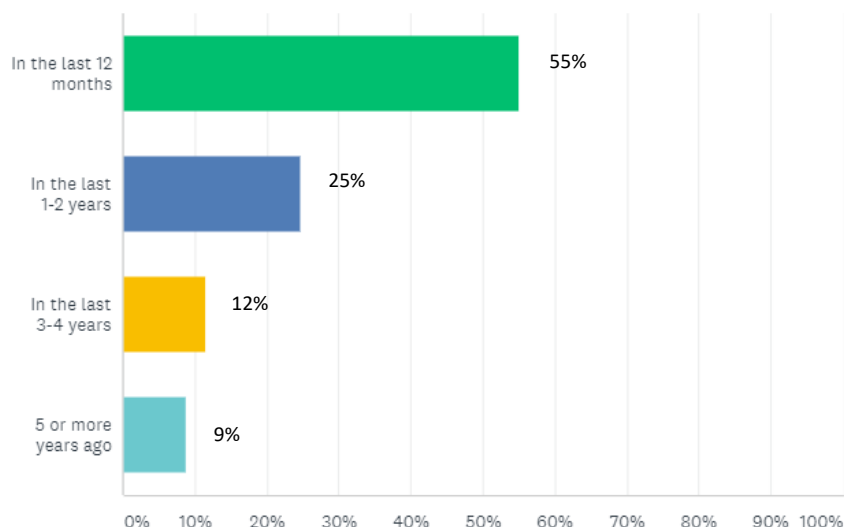
ANSWER CHOICES	RESPONSES	
▼ 1-10	69.74%	53
▼ 11-20	5.26%	4
▼ 21-40	2.63%	2
▼ >40	13.16%	10
▼ None	9.21%	7
TOTAL		76

Figure 2 shows that regardless of specialty, many providers (70%) indicated that they currently manage between one and ten patients with HIV/AIDS, compared to 65% last year.

Figure 3: Consultation of Current Treatment Guidelines and New HIV/AIDS Recommendations

How recently have you consulted treatment guideline changes and new recommendations for patients living with HIV/AIDS? (e.g. Infectious Disease Society of America, National Institute of Health, HIVinfo., CDC, etc.)

Answered: 69 Skipped: 7



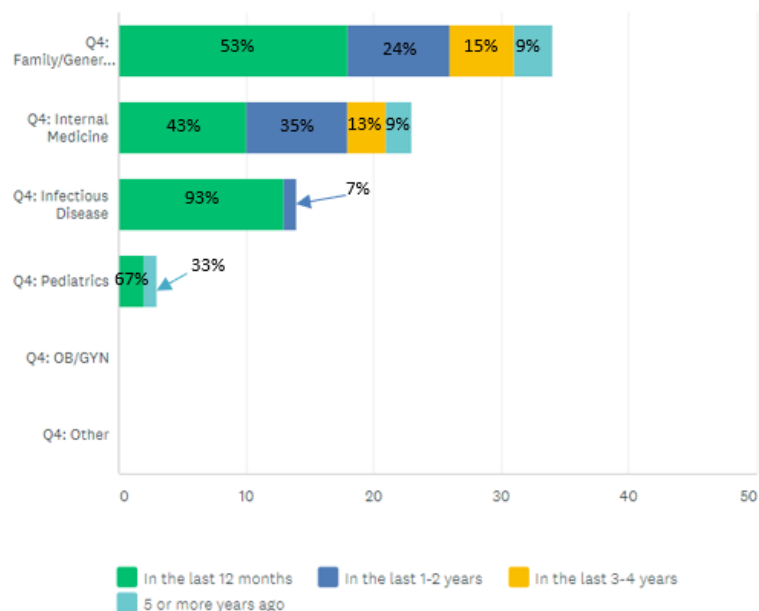
ANSWER CHOICES	RESPONSES	
In the last 12 months	55.07%	38
In the last 1-2 years	24.64%	17
In the last 3-4 years	11.59%	8
5 or more years ago	8.70%	6
Total Respondents: 69		

Figure 3 shows providers' timeframe for consulting current treatment guidelines and new recommendations for HIV/AIDS patients. More than half (55%) indicate they have reviewed the guidelines in the last 12 months; this is a 15% decrease from the previous year. Nine percent of providers indicated that it has been five or more years since they reviewed treatment guidelines and recommendations, compared to 8% last year.

Figure 3a: Practice Type and Consultation of New HIV/AIDS Guidelines and Recommendations

How recently have you consulted treatment guideline changes and new recommendations for patients living with HIV/AIDS? (e.g. Infectious Disease Society of America, National Institute of Health, HIVinfo., CDC, etc.)

Answered: 69 Skipped: 7



	IN THE LAST 12 MONTHS	IN THE LAST 1-2 YEARS	IN THE LAST 3-4 YEARS	5 OR MORE YEARS AGO	TOTAL
Q4: Family/General Practice	52.94% 18	23.53% 8	14.71% 5	8.82% 3	49.28% 34
Q4: Internal Medicine	43.48% 10	34.78% 8	13.04% 3	8.70% 2	33.33% 23
Q4: Infectious Disease	92.86% 13	7.14% 1	0.00% 0	0.00% 0	20.29% 14
Q4: Pediatrics	66.67% 2	0.00% 0	0.00% 0	33.33% 1	4.35% 3
Q4: OB/GYN	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0
Q4: Other	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0
Total Respondents	38	17	8	6	69

Figure 3a shows providers' timeframe for consulting current treatment guidelines and new recommendations for HIV/AIDS patients by provider specialty. Ninety-three percent of infectious disease specialists that responded indicated that they had reviewed the new HIV/AIDS guidelines and recommendations within the last 12 months. Other specialties had lower rates of review within the previous 12 months.

Figure 3b: Current HIV/AIDS Patients for Infectious Disease Specialists

How many patients living with HIV/AIDS have you medically managed or co-managed (for any diagnosis) in the last 12 months?

Answered: 14 Skipped: 0

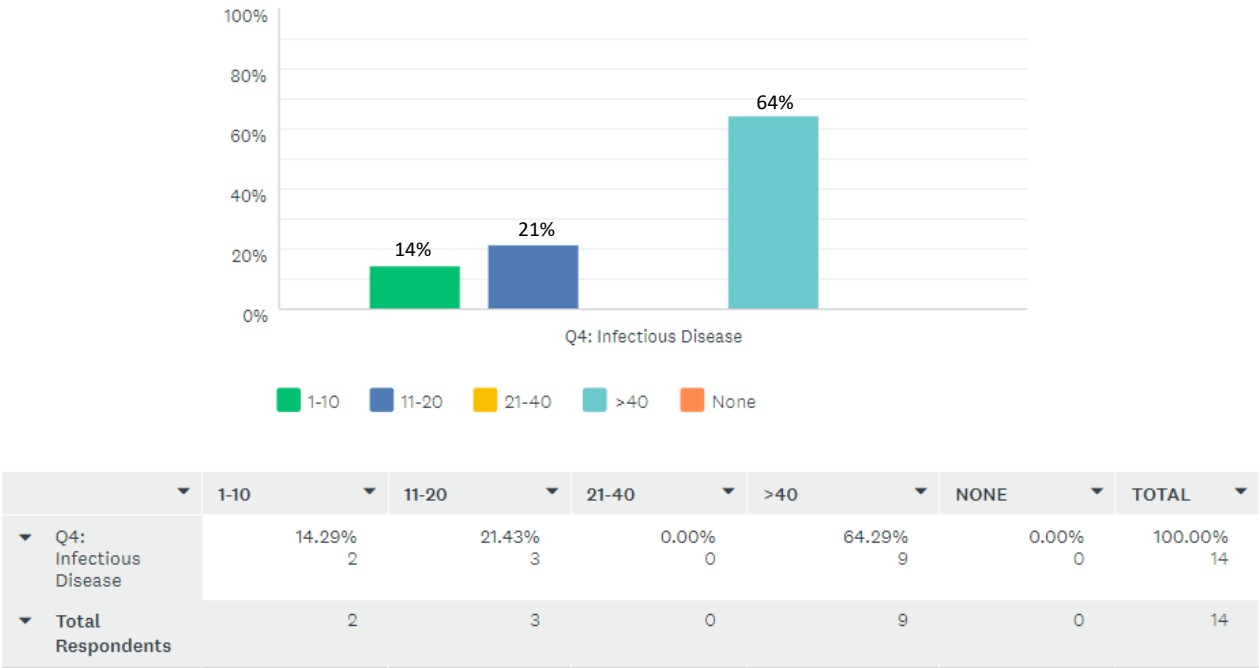
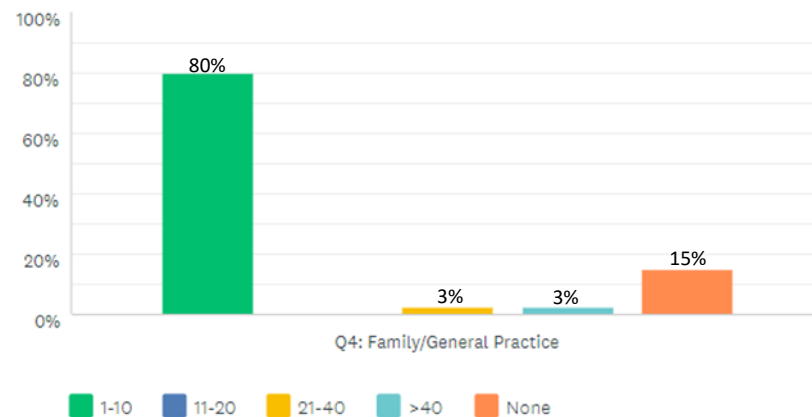


Figure 3b shows how many patients are managed by the infectious disease specialists who responded to the survey. Nine out of 14 infectious disease specialists indicated that they currently manage over 40 patients, compared to seven of twelve the previous year.

Figure 3c: Current HIV/AIDS Patients for General/Family Practice

How many patients living with HIV/AIDS have you medically managed or co-managed (for any diagnosis) in the last 12 months?

Answered: 40 Skipped: 0



	1-10	11-20	21-40	>40	NONE	TOTAL
Q4: Family/General Practice	80.00% 32	0.00% 0	2.50% 1	2.50% 1	15.00% 6	100.00% 40
Total Respondents	32	0	1	1	6	40

Figure 3c shows the number of patients treated by the family/general practice respondents. The majority (80%) of family/general practice respondents indicated that they currently manage 1-10 patients with HIV/AIDS, compared to last year, where more providers reported seeing patients in the higher ranges. Three percent of the general/family practice providers who responded indicated that they currently manage over 40 patients with HIV/AIDS, compared to two percent the previous year.

Figure 4: Barriers Providers Perceive to Medication Adherence/Compliance

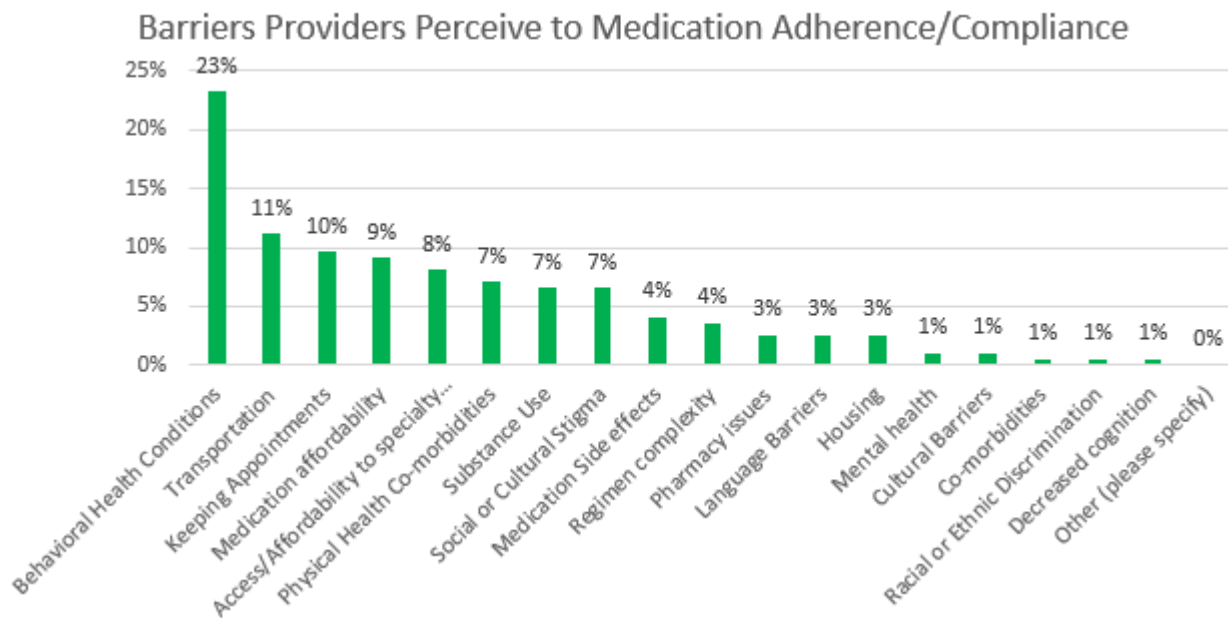
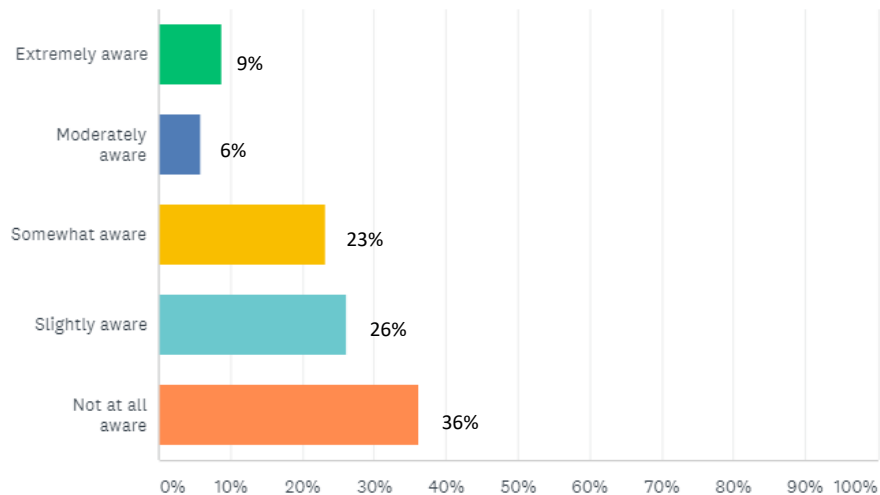


Figure 4 shows what providers feel are the most common barriers related to medication adherence/compliance for their patients with HIV/AIDS. Twenty-three percent of providers indicated behavioral health conditions, 11% indicated transportation, and 10% identified keeping appointments as a top adherence/compliance barrier. These barriers largely match those providers identified in 2019, which were behavioral health (20%), keeping appointments (15%), and transportation (12%). Since 2015, providers have consistently ranked behavioral health conditions the number one barrier to treatment adherence. Transportation and keeping appointments have been in the top three most commonly cited barriers since 2016.

Figure 5: Awareness of HIV Training and Funding Opportunities

Please indicate your awareness of the following: Training and funding opportunities through the Maine AIDS Education and Training Center (MEAETC)

Answered: 69 Skipped: 7



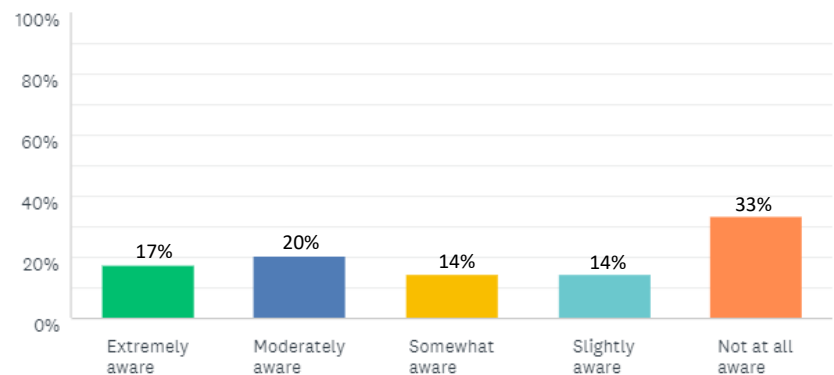
ANSWER CHOICES	RESPONSES	
Extremely aware	8.70%	6
Moderately aware	5.80%	4
Somewhat aware	23.19%	16
Slightly aware	26.09%	18
Not at all aware	36.23%	25
Total Respondents: 69		

Figure 5 shows that 64% of providers have some familiarity with HIV training and funding opportunities through the Maine AIDS Education and Training Center (MEAETC), compared to 73% the previous year. Thirty-six percent of providers were not aware of the MEAETC, compared to 27% the previous year.

Figure 6: Awareness of the Special Benefit Waiver

Please indicate your awareness of the following: MaineCare’s Special Benefit Waiver for individuals living with HIV/AIDS who are not eligible for regular MaineCare

Answered: 69 Skipped: 7



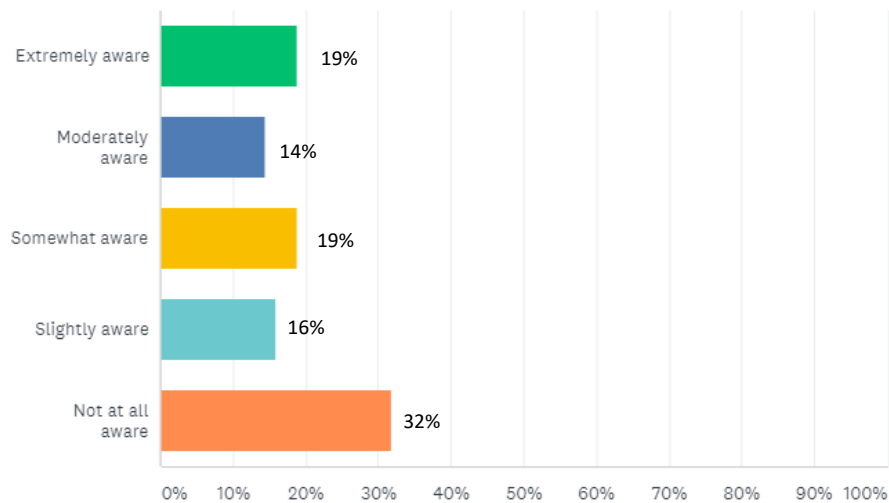
ANSWER CHOICES	RESPONSES	
Extremely aware	17.39%	12
Moderately aware	20.29%	14
Somewhat aware	14.49%	10
Slightly aware	14.49%	10
Not at all aware	33.33%	23
Total Respondents: 69		

Figure 6 shows that most respondents (67%) have some familiarity with Maine’s HIV/AIDS waiver, compared to 75% last year. Thirty-three percent of respondents were not at all aware of the waiver program, compared to 25% last year.

Figure 7: Awareness of Ryan White/ADAP Programs

Please indicate your awareness of the following: The Ryan White/AIDS Drug Assistance Program (ADAP) and the financial assistance they offer (i.e. dental, housing, food, heat, copayments and premiums)

Answered: 69 Skipped: 7



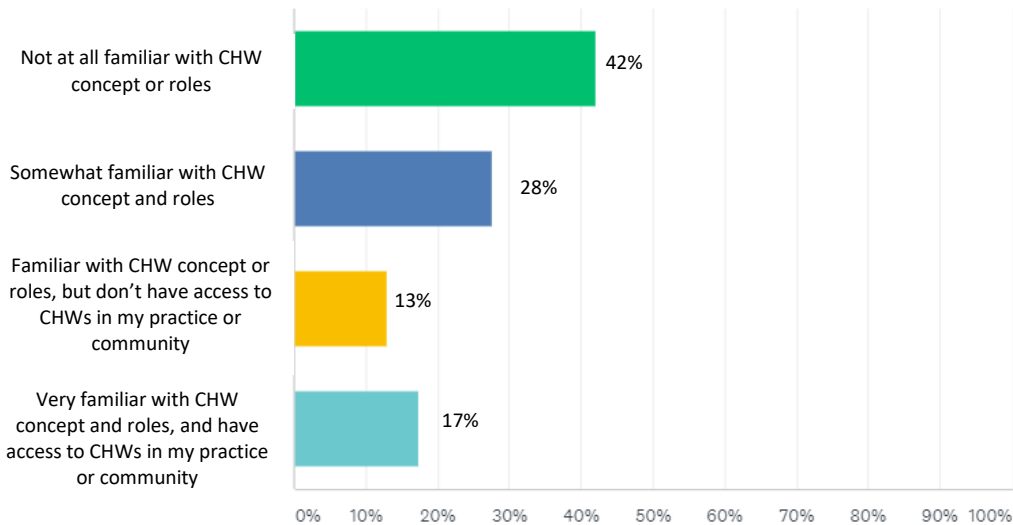
ANSWER CHOICES	RESPONSES	
Extremely aware	18.84%	13
Moderately aware	14.49%	10
Somewhat aware	18.84%	13
Slightly aware	15.94%	11
Not at all aware	31.88%	22
Total Respondents: 69		

Figure 7 shows that 68% of providers are familiar with the Ryan White/AIDS Drug Assistance Program (ADAP), available through the Maine Center for Disease Control & Prevention (CDC), and the financial assistance it offers to people living with HIV/AIDS, compared to 74% last year. Thirty-two percent of providers indicated that they are not at all aware of this program, compared to 26% last year.

Figure 8: Familiarity with CHW concept and roles

Indicate your level of familiarity with CHWs in helping patients in your practice navigate the health care system.

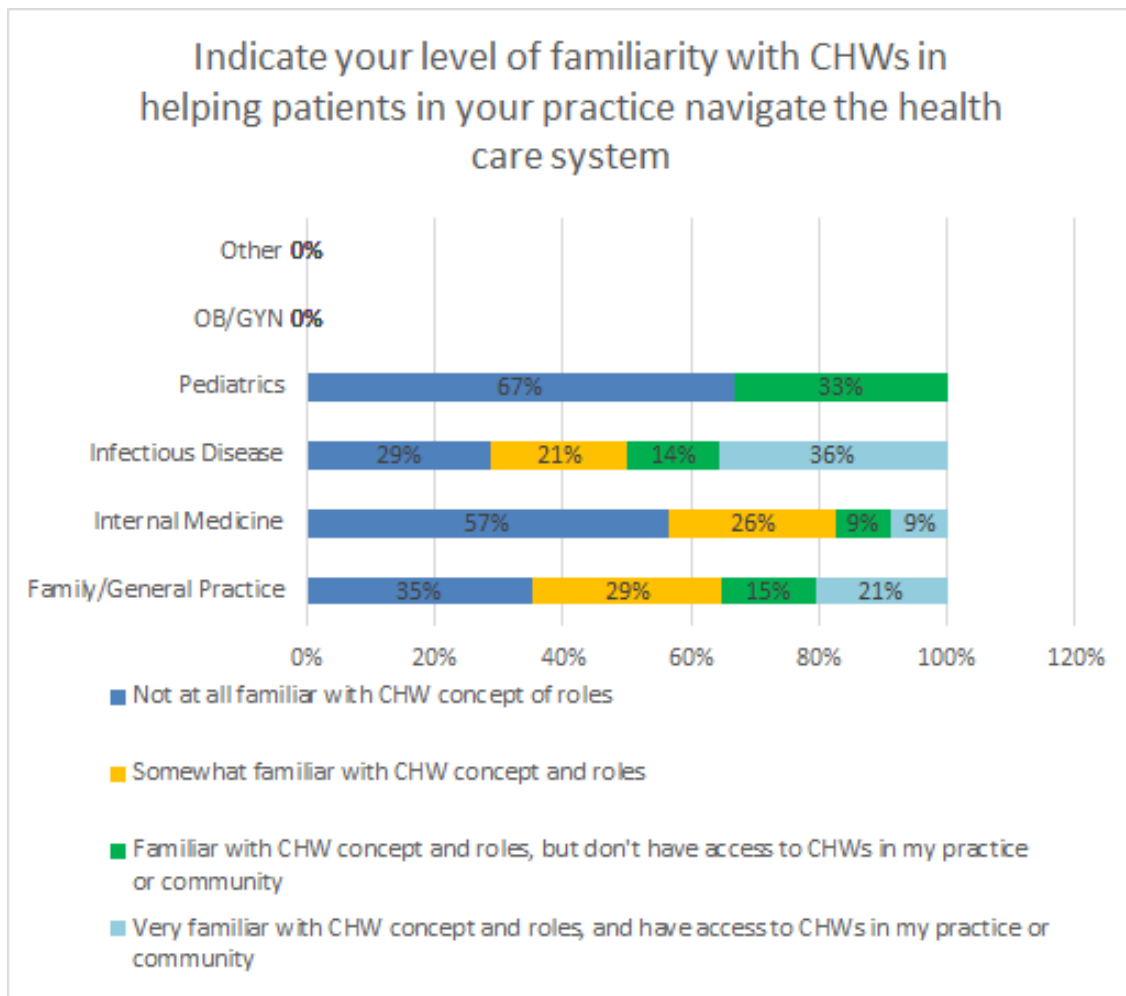
Answered: 69 Skipped: 7



ANSWER CHOICES	RESPONSES	
▼ Not at all familiar with CHW concept or roles	42.03%	29
▼ Somewhat familiar with CHW concept and roles	27.54%	19
▼ Familiar with CHW concept and roles, but don't have access to CHWs in my practice or community	13.04%	9
▼ Very familiar with CHW concept and roles, and have access to CHWs in my practice or community	17.39%	12
Total Respondents: 69		

Figure 8 displays information regarding providers' familiarity with CHWs. These healthcare professionals provide culturally competent care directly in a community setting. This year's survey is the first to ask about provider familiarity of and referral to CHW services. Providers showed varying degrees of knowledge, with 58% responding that they are at least somewhat familiar with the concept and roles of a CHW.

Figure 8a: Familiarity of various provider type with CHW and roles



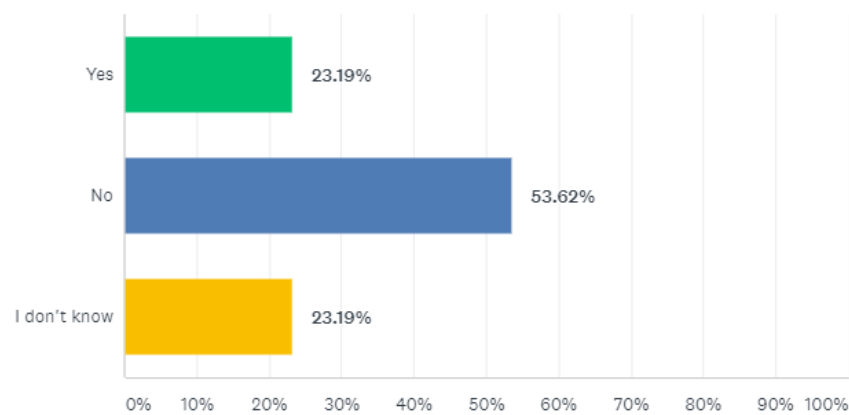
	Q4: FAMILY/GENERAL PRACTICE	Q4: INTERNAL MEDICINE	Q4: INFECTIOUS DISEASE	Q4: PEDIATRICS	Q4: OB/GYN	Q4: OTHER	TOTAL
▼ Not at all familiar with CHW concept or roles	41.38% 12	44.83% 13	13.79% 4	6.90% 2	0.00% 0	0.00% 0	42.03% 29
▼ Somewhat familiar with CHW concept and roles	52.63% 10	31.58% 6	15.79% 3	0.00% 0	0.00% 0	0.00% 0	27.54% 19
▼ Familiar with CHW concept and roles, but don't have access to CHWs in my practice or community	55.56% 5	22.22% 2	22.22% 2	11.11% 1	0.00% 0	0.00% 0	13.04% 9
▼ Very familiar with CHW concept and roles, and have access to CHWs in my practice or community	58.33% 7	16.67% 2	41.67% 5	0.00% 0	0.00% 0	0.00% 0	17.39% 12
▼ Total Respondents	34	23	14	3	0	0	69

Figure 8a shows survey respondents’ current familiarity with CHWs by provider type. Similar to Figure 8, this shows a varying level of familiarity and displays the wide range of provider knowledge by provider type. The infectious disease practices seem to have the most familiarity with and use of CHWs.

Figure 8b: Current referral to a CHW

Do you/your practice currently refer patients to a Community Health Worker (CHW)?

Answered: 69 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	23.19%	16
No	53.62%	37
I don't know	23.19%	16
Total Respondents: 69		

Figure 8b shows survey respondents’ current referral habits to CHWs. It is notable that many providers (54%) do not currently refer patients to a CHW.

Figure 8c: Current referral to a CHW by provider focus

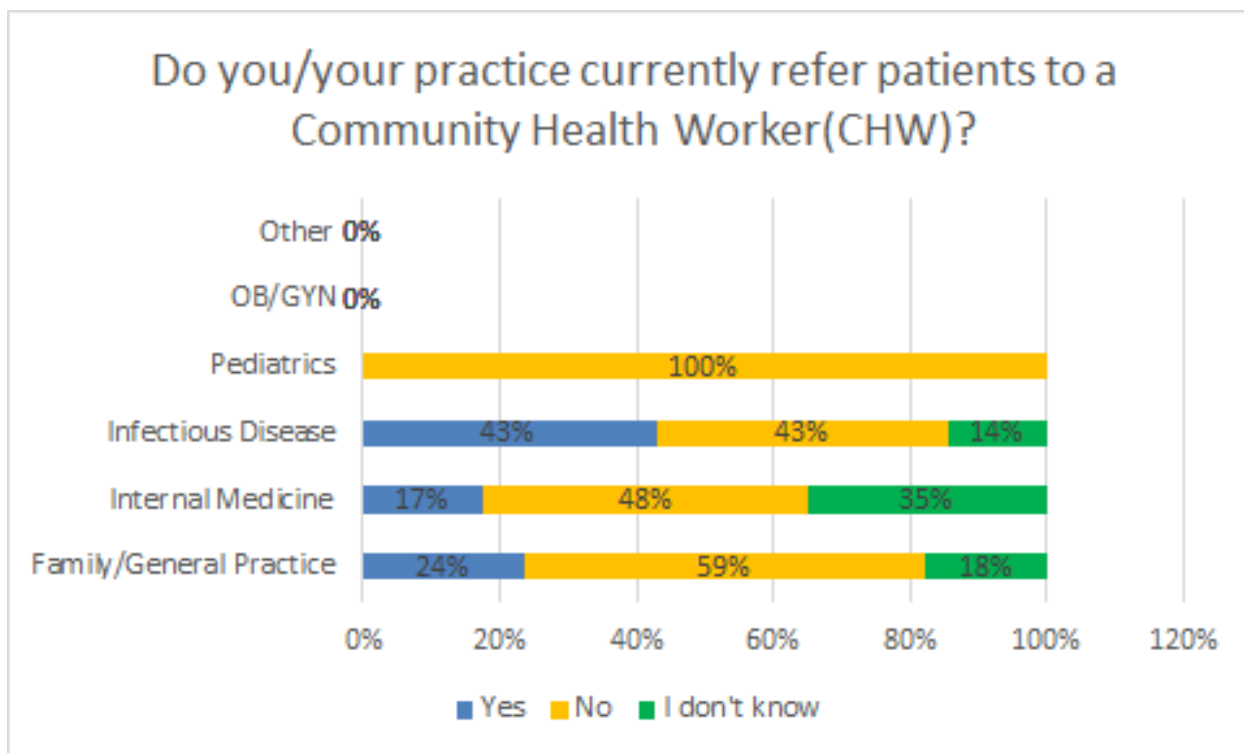
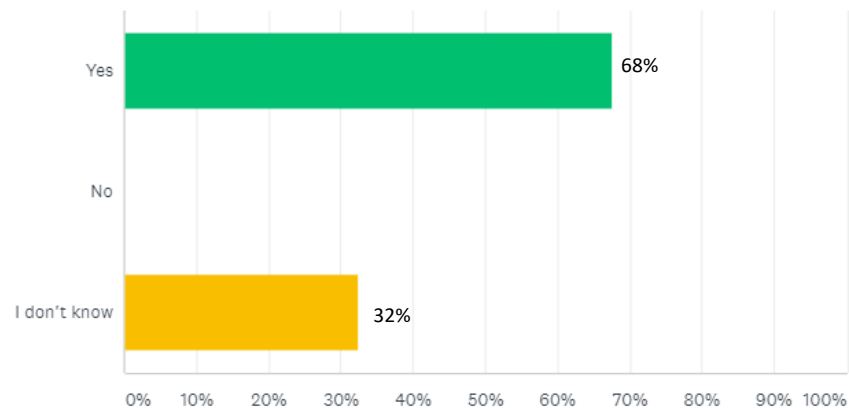


Figure 8c shows providers current CHW referral habits by provider type. Notably, the majority of respondents (37/69) do not currently refer patients to a CHW. Similar to the above finding on providers familiarity of CHW services, infectious disease practices are most likely to have referred patients to CHW services.

Figure 8d: Provider willingness to refer patients to a CHW

If there was a Community Health Worker (CHW) available to work with patients living with HIV/AIDS in your practice, would you refer patients/use this service to help with barriers you identified in figure 4 above?

Answered: 68 Skipped: 8



ANSWER CHOICES	RESPONSES
Yes	67.65% 46
No	0.00% 0
I don't know	32.35% 22
Total Respondents: 68	

Figure 8d displays the responses to if providers would refer patients to CHWs to help address the barriers to treatment adherence that they identified earlier in the survey if CHWs were available (see Figure 4 above). Sixty-eight percent of respondents indicated yes. Of note, there were no respondents that indicated that they would not refer to a CHW, showing that this is potentially a large opportunity to promote the services of CHWs.

Figure 8e: Focus of CHW work

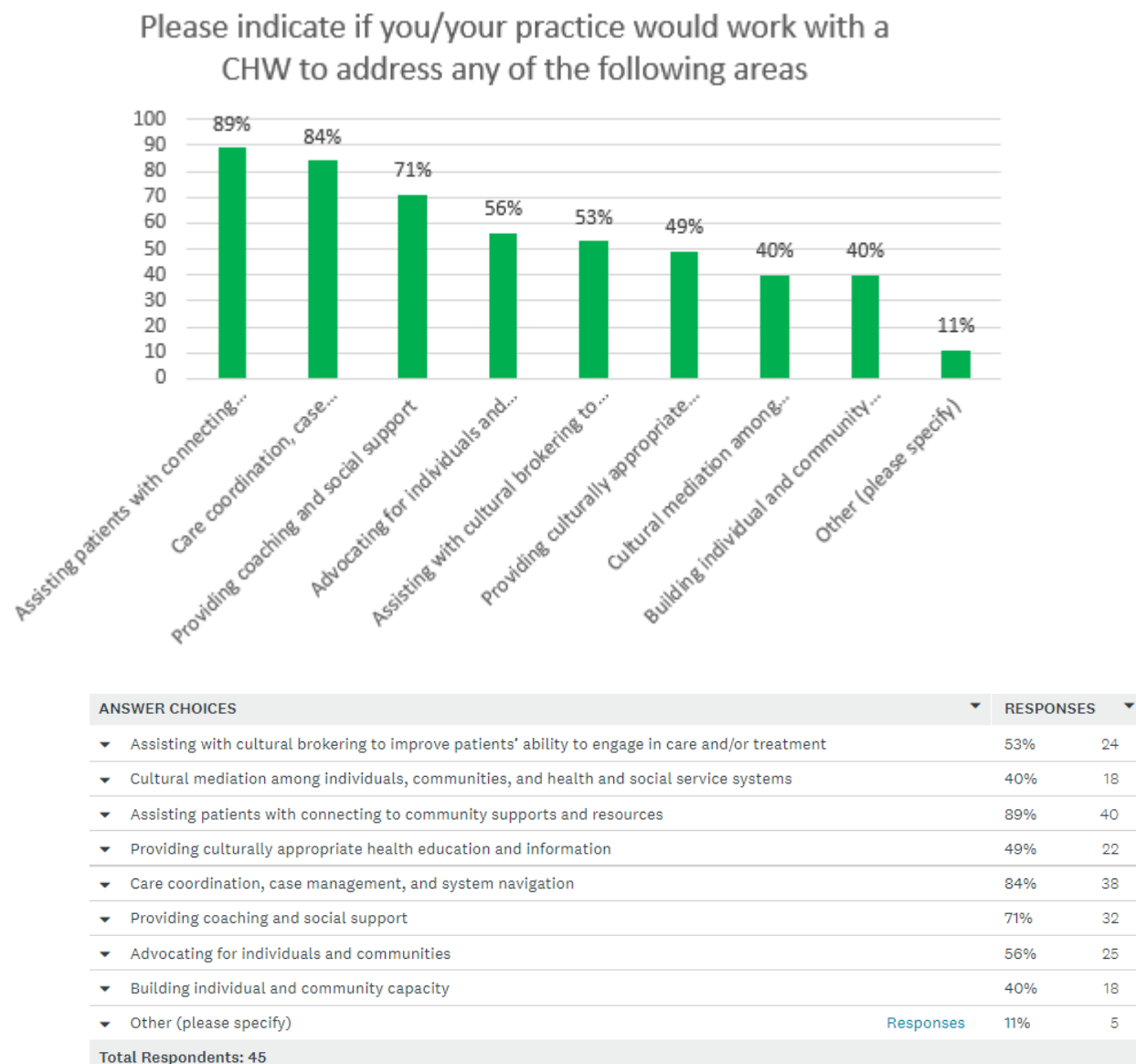
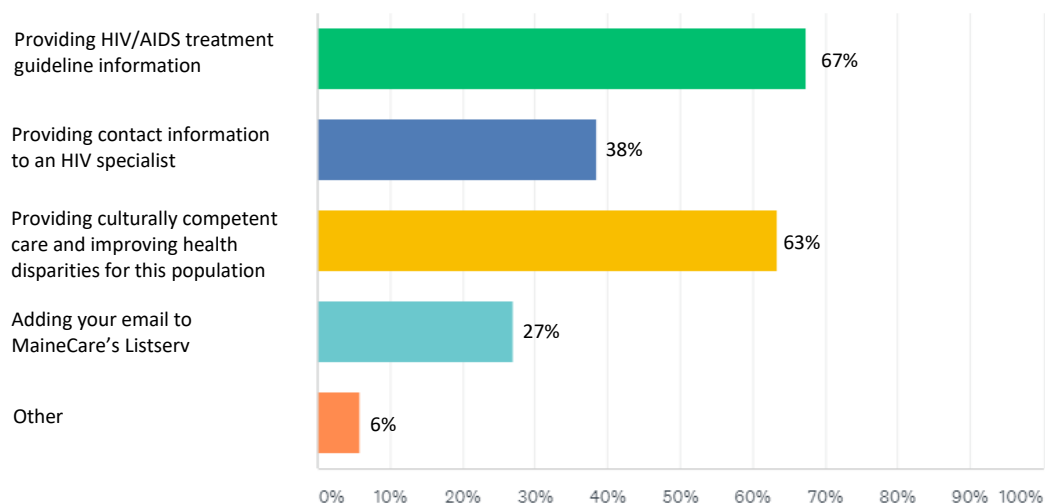


Figure 8e shows for the providers who are willing to refer to a CHW, what areas would be helpful to their practice. The two categories with the highest responses were “assisting patients with connecting to community support and resources” (89%) and “care coordination, case management, and system navigation” (84%).

Figure 9: Support for Providers and Patients

Tell us how the HIV/AIDS waiver program can help you and your patients living with HIV/AIDS. Please check all that apply.

Answered: 52 Skipped: 24



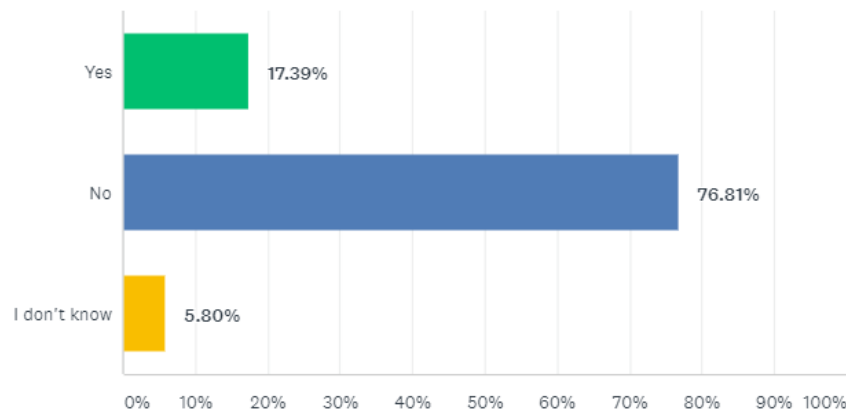
ANSWER CHOICES	RESPONSES	
Providing HIV/AIDS treatment guideline information	67.31%	35
Providing contact information to an HIV specialist	38.46%	20
Providing culturally competent care and improving health disparities for this population	63.46%	33
Adding your email to MaineCare's Listserv (please provide your email address above.)	26.92%	14
Other (please specify)	5.77%	3
Total Respondents: 52		

Figure 9 indicates how providers would like the HIV/AIDS waiver program to support them. This question was added this year. Of the 76 providers who responded, 27% indicated that they wanted to be added to MaineCare's e-mail distribution list; 67% of respondents said that the program should provide treatment guideline information; 63% would like support providing culturally competent care and improving health disparities within the population; 38% of providers would like the HIV/AIDS waiver program to provide contact information for an HIV specialist.

Figure 10: New Mainers

Are any of your patients living with HIV/AIDS New Mainers (newly established in the US)?

Answered: 69 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	17.39%	12
No	76.81%	53
I don't know	5.80%	4
TOTAL		69

Figure 10 shows provider responses regarding whether their HIV/AIDS patients are New Mainers (immigrants newly established in the United States). Most providers (77%) said their patients were not New Mainers.

Figure 10a: Number of New Mainers

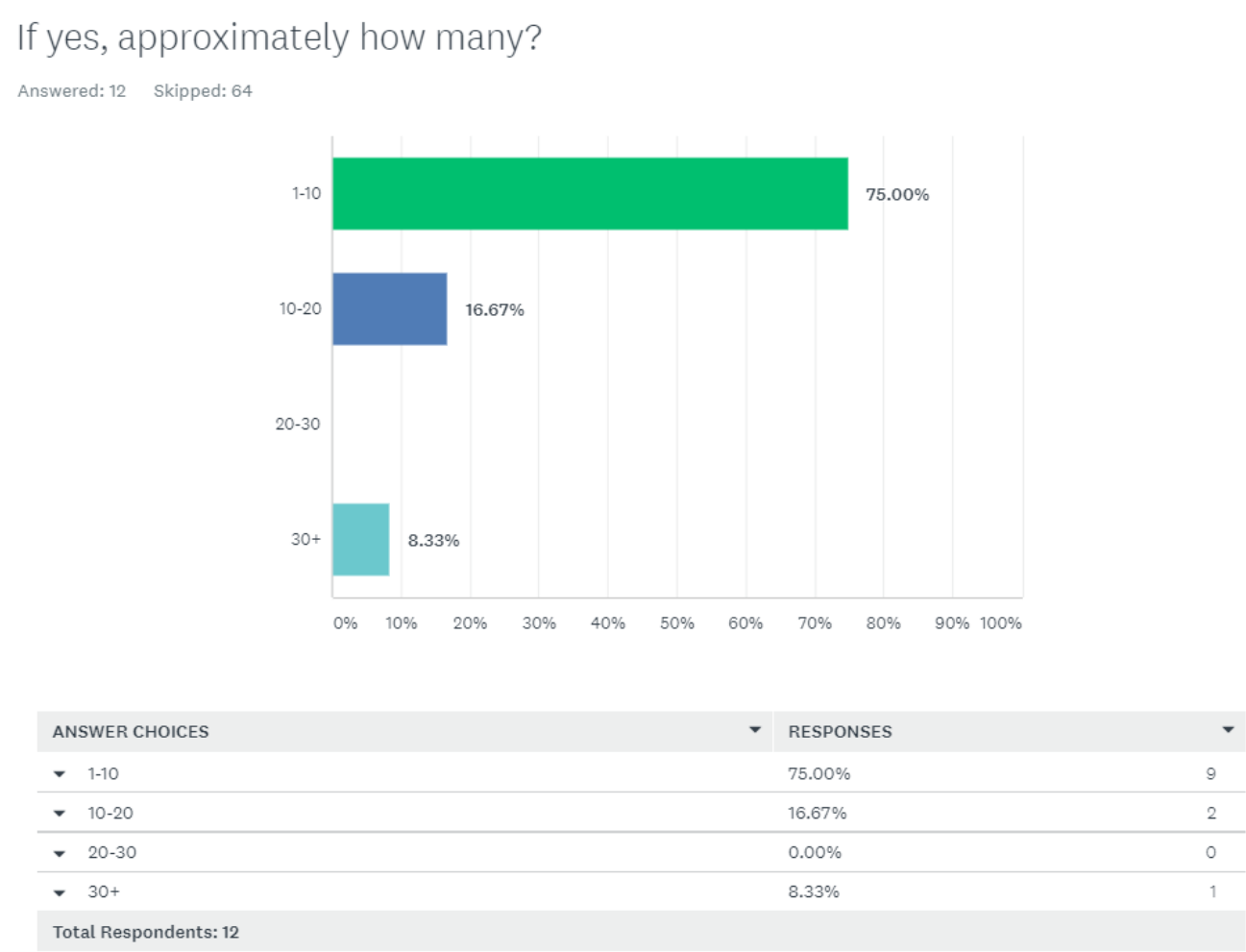
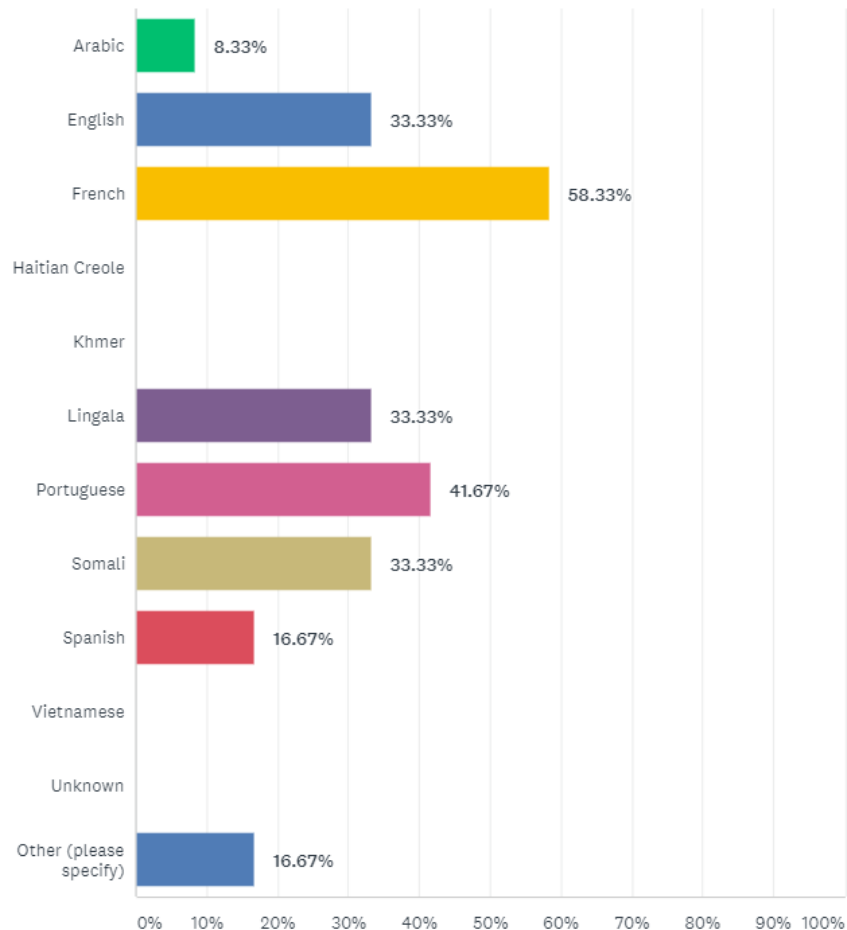


Figure 10a depicts a further breakdown of the New Mainer population to show approximately how many New Mainers providers are currently managing. Most respondents (9 out of 12) reported managing 1-10 New Mainers, whereas only one provider manages more than 30.

Figure 10b: Languages of HIV/AIDS New Mainers

What languages do your New Mainer patients, such as immigrants and refugees, speak?

Answered: 12 Skipped: 64



ANSWER CHOICES	RESPONSES	
Arabic	8.33%	1
English	33.33%	4
French	58.33%	7
Haitian Creole	0.00%	0
Khmer	0.00%	0
Lingala	33.33%	4
Portuguese	41.67%	5
Somali	33.33%	4
Spanish	16.67%	2
Vietnamese	0.00%	0
Unknown	0.00%	0
Other (please specify)	Responses 16.67%	2
Total Respondents: 12		

Figure 10b shows a breakdown of languages New Mainer patients speak based on respondents' experiences inside their respective practices. Only respondents who indicated they have a New Mainer in their practice were asked this question. These 12 providers indicated that the most spoken language (58%) was French, followed by Portuguese (42%). Additionally, many New Mainers speak more than one language.

Key Findings and Next Steps:

The primary goal of the HIV/AIDS waiver program is to improve care and treatment adherence for MaineCare members living with HIV/AIDS. Evidence of the program's success is shown by the fact that 82% of members in 2020 have reached viral suppression (<200 MLs). We celebrate this finding at the same time OMS continues to pursue further opportunities to improve the program to support HIV/AIDS care and care management.

The 2020 Provider Survey responses highlight opportunities for additional program support including:

- Assisting members in finding behavioral health providers and services and access to transportation. Providers indicated these as the top barriers for patients living with HIV/AIDS that prevent maintaining adherence to treatment and obtaining their health goals. These issues are also identified as barriers by respondents to the 2020 Member Survey).
- Directing providers to the latest HIV treatment guidelines.

- Promoting the Maine AIDS Education and Training Center (MEAETC) and other support programs for offering educational opportunities about HIV/AIDS to providers.
- Promoting the availability of Community Health Workers (CHW) and the services they offer.
- Providing culturally competent care and improving health disparities for this population.

The following sections address these opportunities in more detail.

Member Barriers to Adherence/Compliance to Treatment: Behavioral Health Conditions

Twenty-three percent of providers indicated behavioral health conditions as a top barrier to patient adherence/compliance. This finding has been consistent for the past six annual provider surveys. The 2020 MaineCare Member Survey revealed that 53% of members reported experiencing poor mental health five or more days a month. OMS' Nurse Coordinator called these members to learn more about why they reported poor mental health. Most members attributed their poor mental health status to COVID (isolation and/or fear of getting the disease), physical ailments, and pain. Additionally, many of these members reported to OMS that it is just “normal” for them to experience poor mental health throughout the month, especially during the winter months. The members also indicated that behavioral health problems persist, in part, because care is not available; providers have long waiting lists and no open capacity to see new patients. In addition, when the Nurse Coordinator contacts a member about a missed appointment or missed medication pick-up, the member often cites poor mental health as the reason. Based on these results, OMS in collaboration with the broader Department and our community partners, are considering how best to support providers and members in receiving the behavioral health care they need. One promising approach is for practices to utilize CHWs (see below) to help connect members to the necessary services.

Member Barriers to Adherence/Compliance to Treatment: Transportation

Eleven percent of providers indicated transportation is a top barrier to patient treatment adherence/compliance. The 2020 Member Survey showed that 51% of members reported not being able to access necessary medical care, tests, treatments, and prescriptions due to transportation. Though members have access to MaineCare's Non-Emergency Transportation (NET) program, which provides free rides to MaineCare covered services, in 2020, the COVID-19 pandemic led to both a shortage of drivers and the cancellation of many elective or non-emergency appointments. Both

members and providers cancelled elective or non-emergency appointments. This increase in cancellations had an impact on driver availability, especially if the cancellation were not made timely enough to allow for rescheduling of the driver. In 2021, the supply of drivers remained lower than before the pandemic, which has placed a strain on the current capacity of the NET program. OMS is working with NET providers to increase their ability to serve our members.

Provider Education

The provider survey results highlighted a need for more provider education. While most respondents (55%) indicate they have reviewed the HIV treatment guidelines in the last 12 months, this is a 15% decrease from the previous year. OMS is working with the New England HIV AIDS Education Training Center to offer a 30-minute webinar on treatment guidelines. This training will occur in early 2022 and will be available as a resource in the future. Additionally, a number of respondents had little or no familiarity with training and funding opportunities through the Maine AIDS Education and Training Center, MaineCare's Special Benefit Waiver, and the Ryan White/AIDS Drug Assistance Program. To address this, OMS mailed 50 education packets after the survey was closed out to providers. Packets included information on these programs and resources and information on the HIV/AIDS Treatment Guidelines Application.

In addition to the resources and training opportunities listed above, the HIV/AIDS program is exploring other options such as using an existing provider email distribution list to send frequent updates and resources; collaborating with the Maine CDC to create, compile, and share information on the treatment guidelines; and collaborating with the MEAETC to address the lack of familiarity on these and other identified topics.

Community Health Workers (CHWs)

Forty-two percent of respondents were not at all familiar with CHWs, but 68% said if there was a CHW available, they would refer patients to them. Respondents anticipated that a CHW would help patients connect to community support and resources, as well as help with care coordination, case management, and system navigation. A review of 61 studies concluded that CHW programs are effective, particularly for low-income groups, in improving cancer prevention and reducing cardiovascular risk. Eight studies of the 61 reviewed supported addressed cost effectiveness and found

the programs cost effective.² HIV program staff are collaborating with OMS' Delivery System Reform programs, as well as partnering with the Maine Center for Disease Control and Prevention on a grant to support CHWs targeted for the BIPOC HIV population in a Federally Qualified Health Center in Portland, the largest city in the state. OMS plans to use the findings from this grant to inform the HIV waiver program providers about potential options to leverage CHWs for their patients. Finally, the Department has a Federal grant for CHW activities to address health disparities uncovered by the COVID epidemic.

² Kim K, Choi JS, Choi E, Nieman CL, Joo JH, Lin FR, Gitlin LN, Han HR. Effects of Community-Based Health Worker Interventions to Improve Chronic Disease Management and Care Among Vulnerable Populations: A Systematic Review. *Am J Public Health*. 2016 Apr;106(4):e3-e28. doi: 10.2105/AJPH.2015.302987. Epub 2016 Feb 18. PMID: 26890177; PMCID: PMC4785041.